

Joe Lombardo
Governor

Richard Whitley,
MS
Director



Cody Phinney,
MPH
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical
Officer

NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES

Date: June 06, 2025

9:35 AM – 10:14 AM

Meeting Locations:

Pursuant to NRS 241.020(3)(a) as amended by Assembly Bill 253 of the 81st Legislative Session, this meeting was convened using a remote technology system and there was no physical location for this meeting.

Chair Annette Logan-Parker opened the meeting at 9:35 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Annette Logan-Parker (Chair); Gina Glass (Vice-Chair); Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Paul Niedermeyer; Christina Thielst, LFACHE, MHA; Sumit Gupta, MD; Kim Anderson-Mackey; Melissa Bart-Plange; Pamela White; Dr. Verena Samara; and Madison Bowe

COUNCIL MEMBERS ABSENT:

Ihsan Azzam, MD, PhD (excused); Brigitte Cole (excused); Naja Bagner (excused); Dr. Devraj Chavda Jennifer Millet, DNP, RN (excused); Amber Federizo, DNP, APRN, FNPBC (excused); Craig Vincze, PhD (excused);

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:

Ashlyn Torrez, *Health Program Specialist I, Office of State Epidemiology (OSE), DPBH*; and Kevin Dodson, *Administrative Assistant III, OSE, DPBH*

OTHERS PRESENT:

Dr. Williams Evans; Nadine Kienhoefer, *Ferrari Reeder Public Affairs*; Amber Williams, *Cure 4 the Kids*; Sabrina Schnur

Roll call was taken and is reflected above. It was determined that there was a quorum of the Rare Disease Advisory Council (RDAC, the Council)

2) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment

Hearing none, Chair Logan-Parker moved on to the next agenda item.

- 11) FOR INFORMATION ONLY: Overview on a summary report of Chair Logan-Parker's legislative activities, including engagement with key Bill Draft Requests (BDRs), Senate Bills (SBs), and Assembly Bills (ABs) in the 83rd Legislative Session (2025). – Chair Annette Logan-Parker

Chair Logan-Parker stated the legislative session had proven to be eventful, with several key bills monitored and supported. [SB348](#) expanded newborn screening through increased fees for the state public health lab, although its provision for licensing genetic counselors had been removed. Licensing for genetic counselors was ultimately secured through [SB189](#), which was signed into law and marked a significant advancement for Nevada. [SB78](#), which had initially proposed changes to the RDAC's role in Nevada, was significantly amended, and the RDAC-related provisions were removed. [SB234](#), focused on Medicaid expansion, and [SB228](#), concerning appropriations for the bone marrow transplant program, both failed to advance through the legislative process.

- 12) FOR INFORMATION ONLY: Update on the Childhood Cancer data collection efforts with Nevada Central Cancer Registry. – Chair Annette Logan-Parker

Chair Logan-Parker reported that the Cenix platform had become fully operational in April, with 164 cases added—140 of which were fully abstracted and submitted to the Nevada State Central Registry. Case finding for 2024 at Cure 4 The Kids had been completed, while 2025 case finding began in June. A total of nine lupus and 251 sickle cell cases were collected and submitted to the state via REDCap.

Ashlyn Torrez stated that the sickle cell and lupus disease dashboard had gone live on the Nevada Office of State Epidemiology website, while updates to the rare conditions dashboard and its algorithm remained in progress. Data from Cure 4 The Kids continued to be uploaded into the Division's REDCap database, with internal meetings planned for data review and cleanup.

Chair Logan-Parker inquired about the plan to inform adult sickle cell treatment providers of reporting requirements and how to support their alignment with the reporting practices established at Cure 4 The Kids.

Ashlyn Torrez responded that an internal discussion had been planned to determine the most effective outreach strategy, with a focus on targeting hematologists directly. A ListServ obtained in December from multiple sources, including the Medicaid database, was intended for direct communication, as previous technical reviews had yielded inconsistent results.

- 3) FOR POSSIBLE ACTION: Approval of minutes from February 7, 2025, Rare Disease Advisory Council Meeting. – *Council Members*

Chair Logan-Parker stated the minutes have been posted on the Department of Health and Human Services (DHHS) website and asked the Council for a motion to approve the minutes.

Councilmember Valerie Porter motioned to approve the meeting minutes from prior council meeting dated 2/07/2025. Councilmember Christina Thielst seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

- 4) FOR POSSIBLE ACTION: Approval of minutes from April 4, 2025, Rare Disease Advisory Council Meeting. – *Council Members*

Chair Logan-Parker stated the minutes have been posted on the Department of Health and Human Services (DHHS) website and asked the Council for a motion to approve the minutes.

Councilmember Valerie Porter motioned to approve the meeting minutes from prior council meeting dated 4/04/2025. Councilmember Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

- 5) FOR POSSIBLE ACTION: Recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to renew Dr. Craig Vincze, PhD, as a member of the Council, pursuant to [NRS 439.5075\(2\)](#), for a term of three years.

Chair Logan-Parker stated Craig Vincze's Curriculum Vitae is posted on the Department of Health and Human Services (DHHS) website and he has expressed interest in serving another three-year term. Chair Logan-Parker asked the Council for a motion to recommend Craig Vincze to renew his role as a member of the Council.

Councilmember Christina Thielst motioned to approve the recommendation of Dr. Craig Vincze to Department of Health and Human Services, Director's Office to renew his appointment to the Council. Councilmember Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the recommendation of Dr. Craig Vincze to Department of Health and Human Services, Director's Office to renew his appointment to the Council. A draft letter of recommendation will be put on the action items.

- 6) FOR POSSIBLE ACTION: Recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to renew Christina Thielst, LFACHE as a member of the Council, pursuant to [NRS 439.5075\(1\)\(b\)\(6\)](#), for a term of three years.

Chair Logan-Parker stated Christina Thielst's Curriculum Vitae is posted on the Department of Health and Human Services (DHHS) website and she has expressed interest in serving another three-year term. Chair Logan-Parker asked the Council for a motion to recommend Christina Thielst to renew her role as a member of the Council.

Councilmember Dr. Sumit Gupta motioned to approve the recommendation of Christina Thielst to Department of Health and Human Services, Director's Office to renew her appointment to the Council. Councilmember Valerie Porter seconded the motion to approve. There were no objections. A quorum voted to approve the recommendation of Christina Thielst to Department of Health and Human Services, Director's Office to renew her appointment to the Council. A draft letter of recommendation will be put on the action items.

- 7) FOR POSSIBLE ACTION: Recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to renew Paul Niedermeyer as a member of the Council, pursuant to [NRS 439.5075\(2\)](#), for a term of three years.

Chair Logan-Parker stated Paul Niedermeyer's Curriculum Vitae is posted on the Department of Health and Human Services (DHHS) website and he has expressed interest in serving another three-year term. Chair Logan-Parker asked the Council for a motion to recommend Paul Niedermeyer to renew his role as a member of the Council.

Councilmember Valerie Porter motioned to approve the recommendation of Paul Niedermeyer to Department of Health and Human Services, Director's Office to renew his appointment to the Council. Councilmember Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the recommendation of Paul Niedermeyer to Department of Health and Human Services, Director's Office to renew his appointment to the Council. A draft letter of recommendation will be put on the action items.

- 8) FOR POSSIBLE ACTION: Discussion and possible action to approve the RDAC Council member survey for feedback in drafting the next RDAC Strategic Plan for 2026-2027, outlining the framework for a collaborative comprehensive care management plan for rare diseases in Nevada.

Chair Logan-Parker stated the survey for RDAC members was developed to assess the Council's activities and effectiveness in preparation for future strategic planning. The survey, edited with assistance from Council Member Paul Niedermeyer, had been circulated for some time; however, final approval had been delayed due to a lack of quorum at the previous meeting. Chair Logan-Parker requested a motion to begin the conversation. The motion passed, and no discussion was required. A motion was then requested to approve the survey.

Councilmember Dr. Verena Samara moved to approve the RDAC Council member survey for feedback in drafting the next RDAC Strategic Plan for 2026-2027. Councilmember Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the RDAC Council member survey for feedback in drafting the next RDAC Strategic Plan for 2026-2027.

- 9) **FOR POSSIBLE ACTION:** Discussion and possible action to approve the social media campaign to showcase RDAC efforts, inform the public about getting involved, and highlight the ‘While You Wait’ Needs Assessment Campaign.

Chair Logan-Parker briefly stated that a comprehensive outline for a social media campaign highlighting RDAC efforts had been developed, detailing the campaign’s background, goals, and weekly topics. The campaign plan had been posted on the RDAC DHHS website and distributed to all council members. Chair Logan-Parker requested a motion to begin the conversation. The motion passed, and no discussion was required. Chair Logan-Parker then requested a motion to approve the social media campaign.

Councilmember Christina Thielst moved to approve the ‘While You Wait’ Needs Assessment Campaign. Councilmember Melissa Bart-Plange seconded the motion to approve. There were no objections. A quorum voted to approve the ‘While You Wait’ Needs Assessment Campaign.

Council Member Melissa Bart-Plange raised a question about whether TikTok had been considered as a platform for the campaign, noting that other councils had received feedback indicating Nevada-related content was appearing on the app, possibly due to influencers in the special needs community.

Chair Logan-Parker stated that she would speak with the digital content and social media manager to determine if TikTok could be added. Chair Logan-Parker then entertained a motion to amend the plan to include the possibility of utilizing TikTok platforms.

Councilmember Christina Thielst moved to approve to amend plan to include the possibility of utilizing TikTok platforms. Councilmember Valerie Porter seconded the motion to approve. There were no objections. A quorum voted to approve the amended plan to include the possibility of utilizing TikTok platforms.

- 10) **FOR POSSIBLE ACTION:** Discussion and possible action to approve to recommend to the Director of Department of Health and Human Services to appoint Dr. William Evans to fulfill the role of an additional member of the Council who has expertise on issues studied by the Council pursuant to [NRS 439.5075\(2\)](#).

Chair Logan-Parker stated Dr. William Evans’s Curriculum Vitae is posted on the Department of Health and Human Services (DHHS) website and he has expressed interest in serving another three-year term. Chair Logan-Parker asked the Council for a motion to recommend Dr. William Evans to Department of Health and Human Services for a term of three years.

Dr. William Evans, in 1980, became the first full-time pediatric subspecialist in Nevada and the state’s first full-time pediatric cardiologist. Over the course of 45 years, the program evolved into a top ten congenital heart center in the United States, as recognized by the Society of Thoracic Surgery based on surgical outcome data. The team expanded to include 17 full-time pediatric cardiologists and two congenital heart surgeons, managing about 50,000 patient interactions annually and becoming the second-largest program in the nation. Congenital heart disease, though rare, along with many other

infrequently occurring conditions, placed these patients firmly within the category of those with special health care needs.

Chair Logan-Parker remarked that, over the past 30 years, Dr. William Evans's program had demonstrated significant growth and made deeply appreciated contributions to the state of Nevada. Chair Logan-Parker then requested a motion from the Council to recommend Dr. William Evans to fulfill a role as an additional member of the Council.

Councilmember Dr. Sumit Gupta moved to term approve the recommendation of Dr. William Evans to Department of Health and Human Services, Director's Office, to appoint him for a three term to the Council. Councilmember Melissa Bart-Plange seconded the motion to approve. There were no objections. A quorum voted to approve the recommendation of Dr. William Evans to Department of Health and Human Services, Director's Office, to appoint him for a three to the Council. A draft letter of recommendation will be put on the action items.

13) FOR INFORMATION ONLY: Council member information sharing announcements – *Council Members*

Chair Logan-Parker opened the floor to Council members to share any announcements.

Hearing none, Chair Logan-Parker moved on to public comment.

14) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair Logan-Parker moved on to adjourn the meeting.

15) ADJOURNMENT – *Chair Annette Logan-Parker*

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair Logan-Parker moved on to adjourn the meeting.

Chair Logan-Parker moved to adjourn the meeting at 10:14 am.